

# RENALITY

SOUTH WEST THAMES RENAL & TRANSPLANTATION UNIT, EPSOM & ST HELIER  
UNIVERSITY HOSPITALS NHS TRUST  
SOUTH WEST THAMES KIDNEY FUND SUPPORTING THE SOUTH WEST THAMES  
INSTITUTE FOR RENAL RESEARCH  
ST HELIER & SURREY KIDNEY PATIENTS' ASSOCIATION

**Newsletter** April 2016



## Featuring...

HOLIDAY  
DIALYSIS GUIDE

WORLD  
KIDNEY DAY

SPRING HAS  
SPRUNG

# RENALITY

Newsletter April 2016

There are many many ways in which you can help the **South West Thames Kidney Fund** and help ensure the future of Kidney Research. Further information on all of them can be accessed via the 'support us' page on our new website – or, if you do not have computer access and would like to know more, please do call **020 8296 3698**.

Make a **one-off donation** online, by text to SWKF22£\_ to 70070, or by cheque to

SWTKF, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

Create a **standing order**

Donate via **payroll giving**

Join our weekly **lottery** and play to win!

Shop 'til you drop and **Give as You Live!**

Recycle your old car at no cost via **GiveaCar** Call them on 020 0011 1664

Sell an item on **ebay**

Volunteer **your time** (we can give you all sort of ideas!)

Buy our **Christmas Cards**

Donate **shares**

Donate your **tax refund**

## Useful Contacts:

### RENAL UNIT reception:

020 8296 2283,  
020 8296 3100

### SWTIRR & SWTKF:

020 8296 3698

### SOUTH WEST THAMES

#### KIDNEY FUND,

[info@kidneyfund.org.uk](mailto:info@kidneyfund.org.uk)

### ST HELIER & SURREY KPA

Dave Spensley, Chairman

01483 426276

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## REMEMBER...

### Our website addresses are:

South West Thames Kidney Fund:  
[www.kidneyfund.org.uk](http://www.kidneyfund.org.uk)

South West Thames Institute for Renal Research:  
[www.swtirr.org.uk](http://www.swtirr.org.uk)

St Helier & Surrey Kidney Patient Association  
[www.shskpa.org](http://www.shskpa.org)

The opinions and views expressed in this Newsletter are those of the individual or organisation expressing them. There can be no assumption that such views and opinions are supported by any other subscribing organisation or individual.

RENALITY is sent to all patients of the Renal and Satellite Units automatically unless they have asked not to receive it. If you do not wish to receive this newsletter, please contact Paul Fischer at the Renal Unit on 020 8296 2514.

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# Holiday Dialysis Guide

Thinking of going on holiday or need to dialyse away from home for a short while?

The Trust wishes to support as many people as possible to experience the freedom of going on holiday, and for this reason, we employ a Dialysis Away from Base Coordinator to support you in arranging this.

**DO NOT BOOK YOUR HOLIDAY/ FLIGHTS UNTIL YOUR DIALYSIS HAS BEEN CONFIRMED.**

Please note that we require a minimum of 6 weeks' notice in order to complete the necessary paperwork.

If you have any queries regarding the information below, please do not hesitate to contact Lindsey.



## So, what should you do?

### BEFORE YOU BOOK

1. Check with your consultant that you are fit to travel.
2. Source the unit closest to where you want to stay. You can use either of the sites below for guidance to help you find the nearest unit.

For the UK:

<http://units.renal.org/?q=0>

For outside the UK:

[www.globaldialysis.com](http://www.globaldialysis.com)

If you are staying with a friend or relative, you can ask them to help you look for local units.

3. Secure your dialysis dates with the unit of your choice. Please note that if they do not have availability for the time you have requested, you may have to find the next closest unit to where you are staying.

4. Once you have secured your dates, contact Lindsey Blazey our Dialysis Away from Base Coordinator on 020 8296 3454 or email [Lindsey.Blazey@esth.nhs.uk](mailto:Lindsey.Blazey@esth.nhs.uk)

You must pass on contact details of the unit, such as contact name, telephone and fax numbers and email so that Lindsey can contact them directly.

5. Lindsey will then liaise with both your home and chosen away from base unit to get your paperwork prepared for your holiday.

### ADDITIONAL INFORMATION

#### Insurance

If traveling to a European country, please ensure your European Health Insurance Card (EHIC) is up to date as most units will ask to see it prior to your arrival. If you do not have one, please visit <http://www.nhs.uk/NHSEngland/Healthcareabroad/EHIC/>

[Pages/about-the-ehic.aspx](http://units.renal.org/Pages/about-the-ehic.aspx) or phone 0845 606 2030 to apply for one.

#### Do I have to pay for dialysis?

Not if you dialyse in the UK or Europe (countries in the European Union) or some countries where we have special arrangements like Australia and Barbados.

If you wish to travel abroad to countries outside the EU and we don't have special arrangements such as South Asia and the USA (check with Lindsey for others) **you will be responsible for dialysis costs** if you travel to these places. This also applies to cruise ships.

#### Transplant waiting list

If you are traveling outside the UK you will be suspended from the transplant waiting list until you return to the UK. Please see the transplant list posters, in the waiting area and Dialysis areas, for suspension and reactivation processes.

# Phosphates – the Additive Effect!

by Caroline Stanbury (Renal Dietitian)

Phosphate is a naturally occurring mineral found in all living things. It occurs in the food we eat, particularly protein-containing foods. Phosphate in the body is mainly found in bones and blood and is kept in balance alongside calcium through absorption from the food we eat in our diet, and excretion in urine and stools.

When our kidneys stop working, their ability to get rid of excess phosphate also decreases resulting in higher than normal levels in the blood. This can cause symptoms such as itching, bone pain and in the long term can

result in weaker bones, increased risk of fractures and hardening of blood vessels. In order to control the body's phosphate levels and stop it building up to levels which may cause damage, renal patients often need to follow a low phosphate diet and may be started on phosphate binders such as Phosex or Calcichew which binds to around 40% dietary phosphate to stop it from being absorbed.

The majority of our renal patients are familiar with the term 'low phosphate diet'. Foods you may think of limiting when on a low phosphate diet might

include cheese, eggs, seafood, oily fish, milk, nuts, and chocolate – (usually followed by "all the foods I love!"). But you may be less familiar with the hidden phosphates contained in many manufactured foods in the form of food additives.

To meet the public demands for fast cooking, appetising, long life foods, the food industry is using increasing numbers of phosphate additives during food processing. Food additives represent a problem for renal patients as they can silently add to a patient's phosphate intake

## Common uses of food additives in food manufacturing or processing:

Food	Function
Baked goods, biscuits, batter, cake mixes	Leavening agent e.g. For dough conditioning and strengthening, lightens and softens baked products
Processed meats	Bind water and meat to increase weight, reduce discoloration and preserve texture
Seafood	Water retention, flesh firming, prevents discolouration, prevent damage due to freezing and crystallisation, used in brine
Cheese	Naturally high in phosphate, added to processed cheese to prevent separation, cottage cheese to reduce pH
Processed drinks	Beverage whiteners, suspension of cocoa in hot chocolate drinks
Rice, pasta, noodles in ready meals or dry food mixes	Speed up cooking times
Milk	To prevent proteins separating
Ice cream	To reduce amount of churning required
Whipped toppings	Foam stabiliser
Frozen potato products	Prevent discolouration
Other every day foods e.g. pre-made ice, salt substitutes, chewing gum, sugar confectionary, cider, fruit wine, salad creams, processed nuts, soups, sauce, vegetable protein drinks, powdered dessert mixes, sports drinks, flavoured drinks, whey protein sports drinks	

Research has found phosphate additives contribute around 500mg of phosphate to the diet, however with increasing intakes of processed foods in society these amounts could be as high as 1000mg which is 100% of the recommended intake of phosphate for

a renal patient. Furthermore, because phosphate additives are inorganic they have higher bioavailability meaning that they are more easily absorbed and therefore more likely to increase blood phosphate levels.

Food manufacturers do not have a

legal requirement to list the amount of phosphate on a nutrition label. Current legislation only requires that food additives present in a product are displayed on the ingredients label however this does not provide any information about the quantities

in the product. Manufacturers can sometimes get around legislation by sourcing composite ingredients from intermediary food producers who are not subject to the same legislation thereby bypassing the need to list all the additives in the food.

**The most common phosphate additives are:**

■ Diphosphates (E450)	■ Phosphoric Acid (E338)
■ Triphosphates (E451)	■ Calcium phosphate (E544)
■ Polyphosphates (E452)	■ Ammonium Phosphate (E545)
■ Monostarch Phosphates (E1410)	■ Others include E101, E240, E339, E341, E343, E442, E540, E541, E542, E627, E631, E1412, E1413, E1414, E1442

**If you have been advised that you need to reduce your phosphate levels, as dietitians we recommend:**

- Following the low phosphate diet sheets you have been given by your dietitian
- Where possible choose fresh foods and produce – 'Fresh is Best'!
- Check labels for the food additives in the list above
- Take your phosphate binders as prescribed – ask your Doctor/Dietitian about timing of binders which can affect the action of the medication
- If you are looking for further information on the internet, choose reliable sources such as the Kidney Foundation, Renal Association or NHS websites

## Challenging Times

In my last article, I set out the three priorities for development in 2016 and I will start by giving an update on these.

First, we have made excellent progress in our effort to improve the dialysis facilities for patients in Croydon. The existing dialysis unit is both overstretched and tired. After a year of searching without success for a suitable location in North Croydon for a new satellite unit, we now are within reach of an even better solution: a new dialysis facility at Croydon Hospital itself. Within a few months, I hope to be able to confirm plans for a major redevelopment that will improve local services and also allow some acute dialysis on the Croydon site.

Second, we continue to work on the development of services in West Surrey, focused on Frimley Park Hospital. We now have firm plans for a regional hub to open there later this year which will minimise the need for patients to travel to St Helier, while retaining all the strengths of a close

attachment to the main renal unit. At the time of writing, we are about to advertise for three new Consultants to lead this exciting new development and I will report further soon.

Third, and not least, we now have advanced plans for the redevelopment of the dialysis service at St Helier itself. In 2017, we hope to move the existing dialysis unit into a new facility at the front of the hospital. This will occupy most of the footprint of the current restaurant, which will be moved elsewhere. This will allow for state-of-the-art facilities in a much more central location, with better access to transport and parking, free Wi-Fi and individual televisions, air conditioning, and co-localisation with acute medical services. It will also allow for the longer term redevelopment of the outpatient, ward and office areas.

These three projects represent a major upgrade of the existing facilities and, once completed, will mean that all the dialysis infrastructure will have been systematically upgraded over the last

6 years. In challenging financial times, and alongside significant service expansion, this is a major achievement.

Speaking of difficult finances, many of you will be aware of the financial challenges affecting the NHS. Our Trust is projecting a deficit this year of £30 million, and up to £40 million for 2016-17. It is on this background that we need to make savings wherever possible. And it is in this light that the above achievements are even more remarkable.

Moving on to clinical matters, I would like to say thank you and farewell to Ayesha Irteza-Ali, who many of you will know has been with us as locum Consultant Nephrologist for the last 15 months. Ayesha is moving to a permanent post at Brighton and we wish her well for the future. Replacing her in a locum role will be another familiar face, Subash Somalanka. It is always pleasing to see how many of

our trainees are keen to stay with us at St Helier, and I know you will all make Subash very welcome.

At the time of writing, we are still awaiting the results of the CQC inspection which took place in November. I will report on this in the next edition. In the interim, we are participating in a London-wide peer review which will see all the London Renal Units inspecting one another in June and July. With luck, this will not only confirm that we are doing all the right things, but will also allow us to share and benefit from examples of best practice.

Lastly, and in association with events that Elsa the Kidney Dog will describe elsewhere, I have been in the unusual position of being a carer rather than a physician over the last few weeks. I come away exhausted and grateful that my family are on the mend. I also come away with profound gratitude to friends and colleagues who have supported us in difficult times, and renewed appreciation of the difficulties faced by so many of you as both patients and carers.

I am aware that we are lucky to have such support. If any reminder was necessary of the privilege of being members of the healthcare community and of the

importance of friends and family, this has certainly been it. You know who you are and we thank you.

**Dr Peter Andrews**  
*Clinical Director*



## Lexie Rose

Lexi Rose was born on 17<sup>th</sup> July 2015 to mum Kerrie who has been on Peritoneal Dialysis since December 2011. The latest recommendations for pregnancy in dialysis patients are 36hours/week of HD (i.e. 6hours/ day for six weeks) this wasn't feasible for Kerrie as she had a young daughter. Kerrie did HD five days a week

and continued on APD every night. To make life easier for her she was dialysed in the PD dept, by the PD staff so she could fit it in around school hours. As far as we are aware this is the first pregnancy to go to full term using dual dialysis, we are very proud of Kerrie and everybody that was involved in making this possible.



# Improving experience for renal patients in London - Survey results:

## Epsom and St Helier University Hospitals NHS Trust

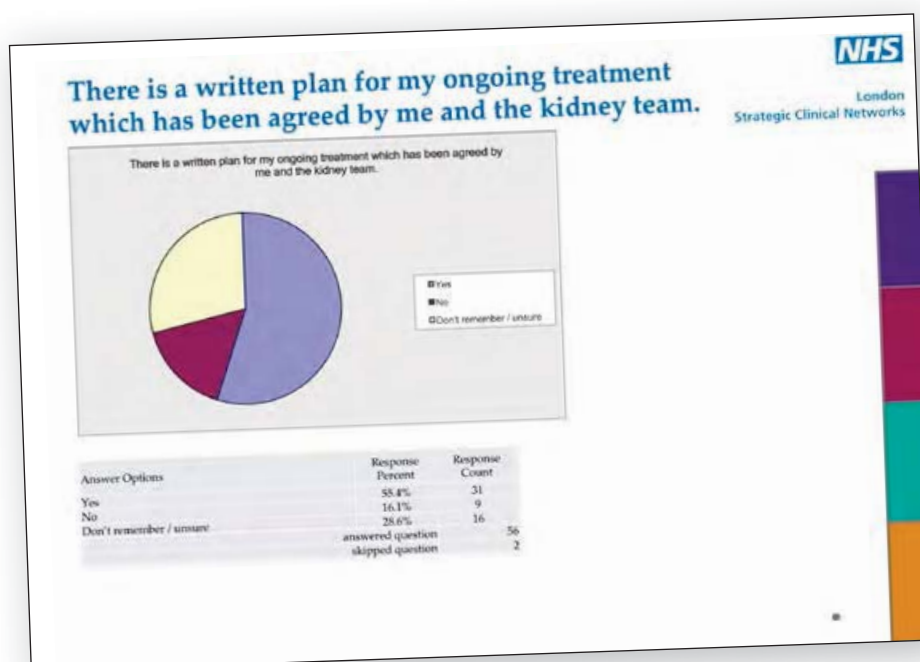
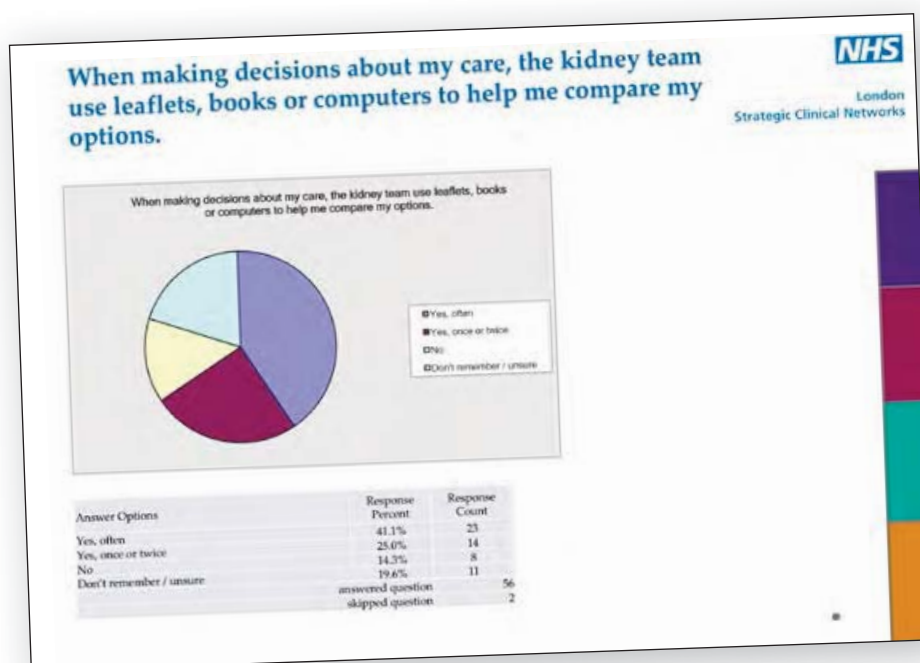


The London Renal Clinic Network surveyed more than 450 haemodialysis patients and 80 peritoneal dialysis patients across London about their experience of care. The patient experience survey was carried out from September to December 2015. Whilst we are delighted to see a high proportion of positive feedback and comments, there is also clearly areas where there is room for improvement.

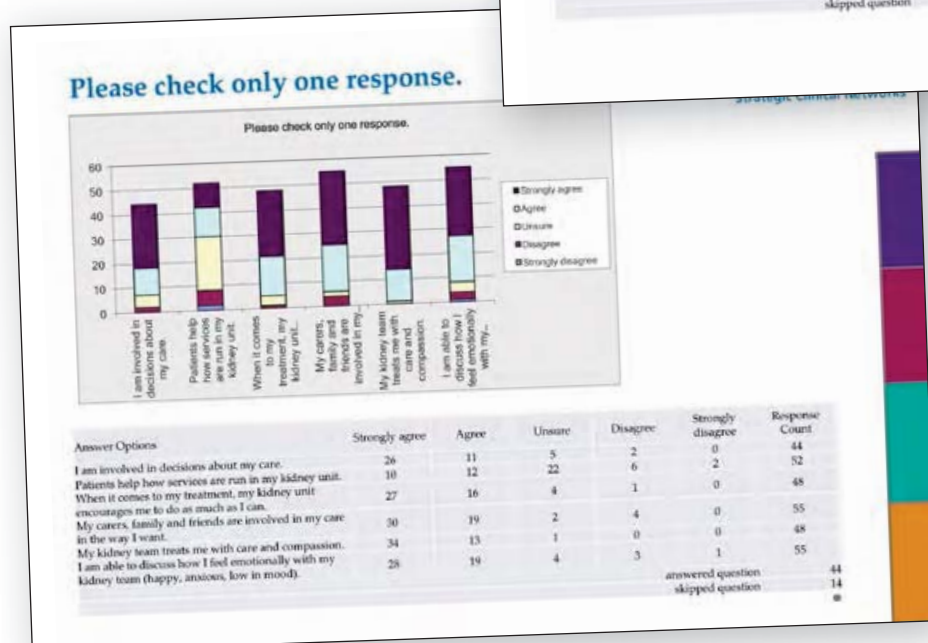
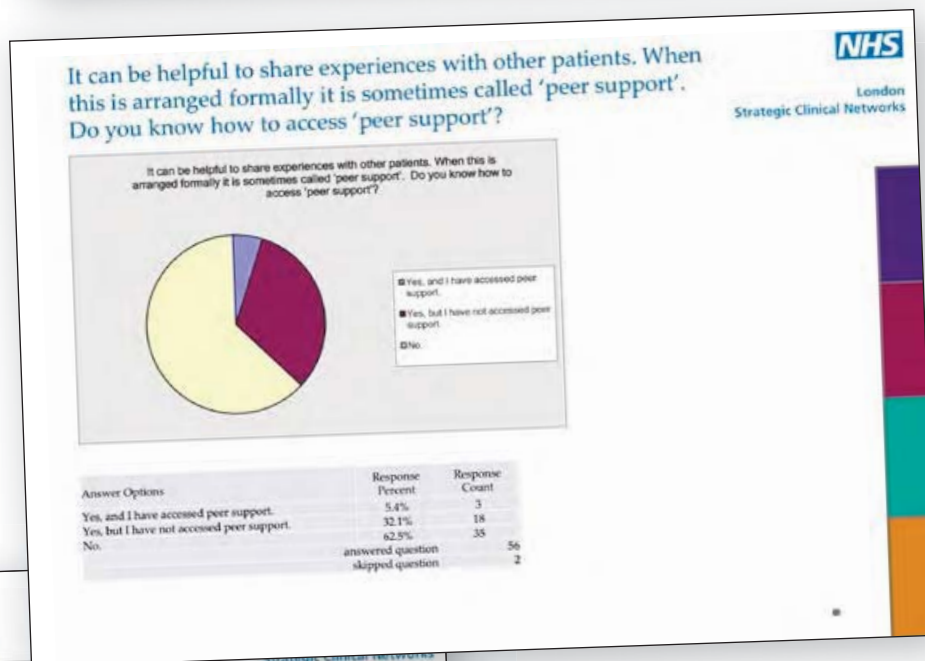
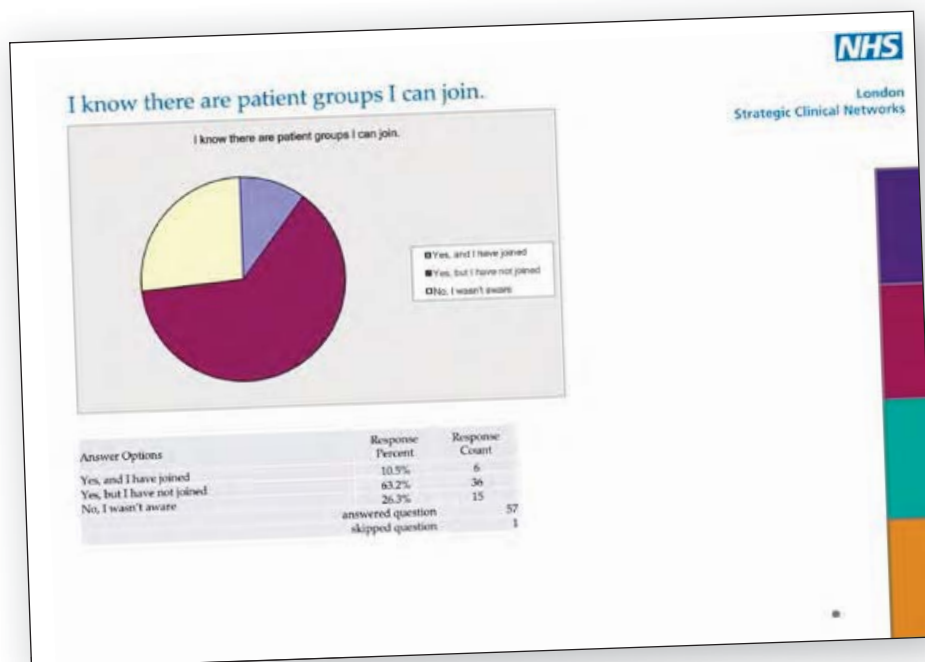
The Renal Unit would like to continue to encourage patients to share their feedback with us, so that we know where we are doing well, but also what we should be improving on.

Please see attached some of our results and free text comments from the survey.

- I have been encouraged to train for home dialysis, which has made a big difference to my way of life. I can't thank the home dialysis unit enough for their encouragement and support.
- The renal staff at St Helier are so dedicated I feel so relaxed there, members of staff will stop and ask me how I am, everyone is so caring. I am a home dialysis patient, the support I have has enabled me to continue working and having dialysis in the comfort of my own home. All nursing staff and doctors work very hard.



- All the care and treatment I have received has been second to none and always picked me up at a time when I felt most unwell. A truly amazing and totally dedicated team.
- Going on home dialysis was not a great idea though it gives me flexibility - because: the workload placed upon my carer is enormous. The responsibility placed upon my carer is very high i cannot dialyse at home alone, i am totally reliant upon my husband/carers and the system takes advantage of him, it offers him as my carer no support whatsoever, he is even having to fight to get a respite week.
- All the staff nurses are nice but only we have to wait for transport for a very long time.



## Recipes of the Month suitable for Renal patients

This recipe was taken from the "Food with Thought" book. Further recipes suitable for people with kidney disease please go here [http://www.kidney.org.uk/documentlibrary/food\\_with\\_thought.pdf](http://www.kidney.org.uk/documentlibrary/food_with_thought.pdf)

### Cod Fillet with Lemon Sauce



SERVES 4

#### Ingredients

4	Cod fillets
1tbsp	Cornflour
1tbsp	Butter or margarine
4tbsp	Water
1	Lemon (grated rind and juice)
Black pepper	

#### Analyses per portion

Energy (kcal)	179	Phosphorus (mmol)	7
Protein (g)	26	Sodium (mmol)	19
Fat (g)	6	Potassium (mmol)	11

#### Method

- 1) Place lemon juice and rind into a small saucepan with the water and bring to the boil.
- 2) Mix the cornflour with a little water and add to the saucepan. Cook, stirring continuously, until thickened. Add pepper to taste.
- 3) Dot the fish with butter (or margarine) and grill for 5-6 minutes each side.

**Serve with...** chips (parboiled before frying or roasting), a boiled vegetable of your choice and the hot lemon sauce.

### Apple and Plum Crumble



#### Ingredients

500g	Cooking apples
100g	Plums
50ml	Water
35g	Caster sugar
¼tsp	Cinnamon

#### Crumble topping

80g	Plain flour
80g	Margarine
80g	Dark brown sugar
55g	Rollled oats
¼tsp	Nutmeg
1tbsp	Honey

#### Method

- 1) Peel, core and slice the apples. Stone and quarter the plums.
- 2) Place the fruit in an ovenproof dish with the water, sugar and cinnamon.
- 3) Rub the margarine and flour together then stir in the dark brown sugar, oats, nutmeg and honey. Spoon the crumble mix over the fruit.
- 4) Bake in an oven at 200°C (Gas Mark 6) for 30 minutes until the crumble is golden brown.

**Serve with...** custard.

#### Analyses per portion (without custard)

Energy (kcal)	458	Phosphorus (mmol)	3
Protein (g)	4	Sodium (mmol)	6
Fat (g)	18	Potassium (mmol)	7

**Note:** Avoid any other fruit during the day. If serving with custard, deduct this from your daily milk and fluid allowance.

# World Kidney Day



The Kidney Fund would like to thank all the volunteers who came along to our 2016 World Kidney Day event at the Bentalls Centre in Kingston upon Thames on March 10th.

With their hard work and enthusiasm they worked throughout the day, asking for donations, handing out balloons, leaflets to raise awareness of kidney disease and raised over £320!.

We also had a visit from the Mayor and Mayoress.

High blood pressure is one of the leading causes of kidney disease and renal unit nurses, Fiona Gilder, Jackie Moore and Anna Kotlikova worked

pretty much non-stop all day doing 'free blood pressure checks' for many passing by.

High blood pressure significantly increases your risk of heart disease, stroke and kidney disease. We urge you to spread the word to your friends, family, work colleagues and acquaintances about the dangers of untreated high blood pressure. When they visit their GP, if they are

not offered a blood pressure check, they should ask for one to be done routinely and as a matter of course.

# Dear all,

I'd like to introduce myself please.

I am a long standing patient of St Helier Hospital Renal Unit having had a slow burning kidney condition since 1991.

Back in the day I was under the care of the legendary Mr Mike Bending, who visited my local Royal Surrey County Hospital.

Following on from Mike's departure from that particular side of things I have been looked after exceptionally well through many highs and lows by the equally legendary Mr Hugh Gallagher.

In May last year, such was the decline of my kidney function that I had my first transplant. I was very lucky in that this came from my 74 year old Mum and despite the usual "bedding in" challenges I'm delighted to say that I'm now feeling rather like Superman.

Anyone who knows me already will be aware that one of my main passions is cycling. This to me has become more than just a hobby as it has critically helped me remain fit right up until transplant, which in turn helped speed up my recovery time, whilst also it's been an essential means to get me back to full health and fitness post-transplant.

I have been a committee member of The Kidney Fund for more than 3 years now, and during that time I am lucky to have been able to raise many thousands of pounds to help our charity, with the incredible support of my family and friends.

You may have read about some of these events here in Renality, for example DibbFest, where I and some loyal friends broke the previous "World 48hr Team Turbo Training World Record"

(cycling on a static training bike) over the weekend of World Kidney Day in 2014 raising £6,800 in the process with live bands and entertainment both day and night.

In September 2014 whilst struggling with a low kidney function I climbed aboard a customised electric hybrid bicycle and smashed the previous "Fastest Lap of Isle of Man TT Circuit by Electric Bicycle" World Record, by an hour and 20 minutes, raising over £2k for The Kidney Fund.

Having had a pretty torrid 2015 but now feeling ready to tackle the world in 2016, an incredible opportunity presented itself to me in March this year.

I was contacted by my fellow colleagues at The Kidney Fund to see if I would be interested in taking a full time position with both The Kidney Fund and SWTIRR as fundraiser and also supporting the day to day running of the institute.

How could I possibly say no!

By the time you read this I will have started in my new role from 6th April. I have some huge ideas for the future, and I really can't wait to get stuck in. This is a big step for The Kidney Fund as in our own words "It's time for us to grow up as a charity".

Whilst charities supporting cancer patients and those with heart conditions are well known nationally and equally deserving, Kidney charities have always seemed to play second fiddle largely due to many peoples lack of knowledge about what our kidneys do and kidney disease itself.

This will be one of my many challenges to raise awareness of ourselves as a charity but also raise the profile of kidney health and the importance of world leading research.

I am truly honoured to be able to play a part in this, to help Mark and his team to continue the breath taking work and research which they do every day, and to help The Kidney Fund continue to support patients, friends and families affected by kidney disease both locally and further afield as we ourselves grow bigger and better.

To achieve all of this I hope I can count upon your support!

And to that point, I will also be here to help you with your fundraising ideas and ambitions too. Now is the time to explore that fundraising idea you've had at the back of your mind for a while but you've never actually done it. Let's sit down and work out a plan to make it happen during 2016, just give me a call or drop me an email and we can get the plans in place.

Alternatively just stop by and say hi as and when you are passing by the Institute, it would be my pleasure to meet you and my door will always be open for a chat.

I look forward very much towards meeting and working with you all.

Best wishes,

**Mat Dibb**  
**07926 322 953**  
**mat@kidneyfund.org.uk**



## Stephan Fowler – New Magazine Designer

I would like to introduce to you all, our new Magazine Designer of Renality: Stephan Fowler.

Stephan has been running his own very successful design company for over 15 years and is also a long standing personal friend. His company specialises in all types of graphic design including brochures, books, flyers, exhibitions, posters, popup stands, livery, large format banners and point of sale material. His company also create websites and e-shots and offers a wide range of photography services.

Firstly though I would like to say a HUGE thank you to Steve Purcell for all of the hard work and long hours he's put in to Renality over the years. What an incredible thing to do and he will never be forgotten for that, I really hope that you stay in touch with us all Steve as I'm sure you will.



When Steve chose to hang up his editorial cap last year we went on the hunt to find a new designer. Stephan immediately sprang to my mind as I have worked with him professionally throughout much of my career.

Despite the daunting prospect of piecing together the jigsaw that is Renality, Stephan did not hesitate to say yes when I asked him for his help - despite his ever growing client list and busy workload.

You will have seen the striking results already in the last issue, and he's certainly put his mark on Renality from the off. I personally think it looks fantastic and demonstrates both Stephan's talent, and also how lucky we are to have him on board as another one of our many volunteers.

This new image takes our magazine to the next level and aligns us perfectly with other exciting plans for the future.

I'm sure that everyone involved with Renality will join me in saying a big thank you to Stephan for all of your on-going hard work and support.

Should you ever require his services, or just to welcome him on board Stephan can be contacted on via the following:

**stephan@artefactdesign.co.uk**  
**www.artefactdesign.co.uk**  
**01483 429 945**

Thanks,

**Mat Dibb**



**artefactdesign**  
print | web | photography



## The 2016 Camberley Car Show takes place in Camberley Town Centre on Saturday 3rd September 10.0am - 4.0pm.

At last year's Show, with the help of everyone involved we managed to raise £8,452.00 with every penny raised donated to Kidney Research.

It was great to see a number of South West Thames kidney patients at the event and we are very grateful to a number of patients and their families, who volunteered and gave up their time on the day to help in collecting donations. Anyone interested in assisting at this year's show, even if only for an hour or two, please contact [kenbonner@btinternet.com](mailto:kenbonner@btinternet.com)

This our fifth year, will have a number of 'star attractions' on display amongst the 200+ vehicles of many eras and makes plus street entertainers, live music, free children's face-painting and of course as a town centre location, lots of shops, restaurants, cafes and bars on hand so come along and join in the fun and, it's all **FREE!**

Please see <http://www.camberleycarshow.co.uk/> for further information.

# Spring has sprung,

the grass has riz, I wonder where the birdies is...



Some of you may remember that last year about this time I was reminiscing a little about the Institutes's past. I mentioned some of the far-sighted individuals in the renal unit at St Helier who had and realised their vision of a research Institute dedicated to diseases related to the kidney. A joint venture between the patients and their hospital prioritising what was important to them: people like the first director of the Institute David Newman; nephrologists, Drs Eisinger, Kwan and Bending; patients and their loved ones like the Simpsons, the Goddens and the Sammons.

Many things have changed since the Institute opened in 1998 and many of these important characters have now moved on but the vision remains. New discoveries have been made by ourselves and others that have refined and reshaped some of our research but we remain unwaveringly focussed on educating health professionals about kidney disease and working on new tests to improve diagnosis and ground breaking research to improve treatment and ultimately find a cure.

As we are all too aware there have also been many changes in the NHS and our own Epsom & St Helier in the last 20 years and although the constitution of the NHS still values research how this is supported and funded is now very different. A document from ESTH only seven years ago stated "The Trust has an understanding that research is a necessary part of the routine clinical activities in ensuring high quality healthcare to our patients". In the current financial situation it appears this "understanding" is less of a priority. If we think it should be a priority we must

make our feelings known.

It is almost inconceivable to me that the Trust would disinvest from the Institute, particularly at this time. The faith of the Kidney Fund and the support of the Trust has created a self-standing Institute dedicated to kidney disease, something unique in the UK. Obviously there is a lot of good research being carried out in universities and hospitals the length and breadth of our scepter'd Isles but there is no other dedicated facility quite like ours; managed and governed by a combination of renal doctors, patients, their friends and families.

The Institute has always been at the forefront of renal research. Topics studied here in the 1990s are now being talked about at European and American meetings; I was just reading that one of the first markers of kidney function pioneered by the Institute, cystatin c, is currently a hot topic at the American Association of Clinical Chemists' conference. Last year Cubilin, studied by Dr Hugh Gallagher at the Institute back in 1998 was being discussed widely at the European Renal Association meeting.

For over 10 years, Dr Phanish and I have studied a possible contributing factor to kidney scarring called CTGF – connective tissue growth factor. At first people weren't much interested, experiments were difficult and they couldn't see the big picture, but we persisted. Last year I got a grant for over £150 000 from Kidney Research UK to continue some of this work, this year two Professors from King's College London approached us to collaborate on more of this work and I have been invited to form an international consortium to do even

more work on the subject. Who would have thought a little patient's research institute by Carshalton could be at the centre of all this?

And of course there is more; our work on k-cadherin in the kidney that gave birth to our K-Cad test for diabetic kidney disease is attracting attention particularly from a Dutch group in Utrecht; our gene expression project with Ionis Pharmaceuticals in California has caught the attention of a major Swedish/British pharmaceutical company; our expertise in kidney cell biology has brought a Belgian company to our doors and with our little start-up company Helier Scientific we are pushing on with the device for rapid diagnosis of bacterial infection in peritoneal dialysis patients, reducing antibiotic overuse and helping to preserve kidney function.

No, this is certainly not time to think about stopping. As our research begins to bear fruit this is the time to reaffirm our commitment to research. Through research we will find a cure!

**By Dr Mark Dockrell**

# Dear Kidney Fund Supporters,

**Our** research is driven by the grit and determination of patients battling against kidney failure, often over many years.

This morning we received a wedding invitation from two great Kidney Fund supporters with quite an exceptional story to tell.



Richard's wife, Carol started on dialysis in the late 1970's at a very young age and with two young daughters to look after. When I first met her, Carol fixed my gaze and said "I must survive for twenty years to see my daughters growing up." For ten years Carol kept going on haemodialysis. In those early days kidney transplantation was quite dangerous and the risk of failure was very high. When the time was right and research had reduced many of the risks, Carol agreed to a transplant from an unknown donor. Despite numerous complications this kept her off dialysis



for some twelve years. When Carol returned to dialysis she again came to see us and said "I need to survive another twenty years to see my grandchildren growing up!". What spirit and inspiration did that show?

Maggie's husband was a very high powered oil engineer and his work took him all over the world; anywhere there were oil wells to be drilled and serviced. Alan had suffered nephritis at the age of 13 years and when we first met him in his early thirties it was obvious that he would need intermittent haemodialysis and eventually a kidney transplant to survive. Alan delayed the start of dialysis for months because he had such a drive to lead as normal a life as possible. Eventually Alan was forced into starting on dialysis and within a few months he had dialysis set up in his home, with wife Maggie working as his Nurse and minder. Alan often asked for routine appointments to

be on a Friday evening and this was a little odd but no problem because the Kidney Unit runs a 24/7 shop. ("Open all Hours" as Ronnie would have said).

Alans' dialysis efficiency and his routine blood test safety checks were terrible. For months I couldn't understand why this was. I then discovered, that instead of dialysing three times a week, Monday Wednesday and Friday, as directed, Alan was dialysing on Saturday and again on Sunday and then he was flying off to the Middle East for the week to do his demanding job in a climate which was not ideal for a patient with kidney failure!

Eventually Alan got his chance of a life changing transplant. Did he then put his feet up for a well-deserved retirement? Not a bit of it. Alan took up new professional responsibilities and challenges in Scandinavia.

Throughout these decades Carol's husband, Richard, and Alans wife

Maggie worked to keep the families going and worked to support dialysis and all the stresses that life threatening illness brings on a personal level. More than that call of duty, they worked tirelessly in the cause of providing and funding Dr Mark Dockrell's Renal Research Institute, at St Helier Hospital.

A number of years after inevitable bereavement Richard and Maggie have requested that friends might celebrate their own marriage, not by presents, but by contributions to The South West Thames Kidney Fund. Let's make this a bumper boost to

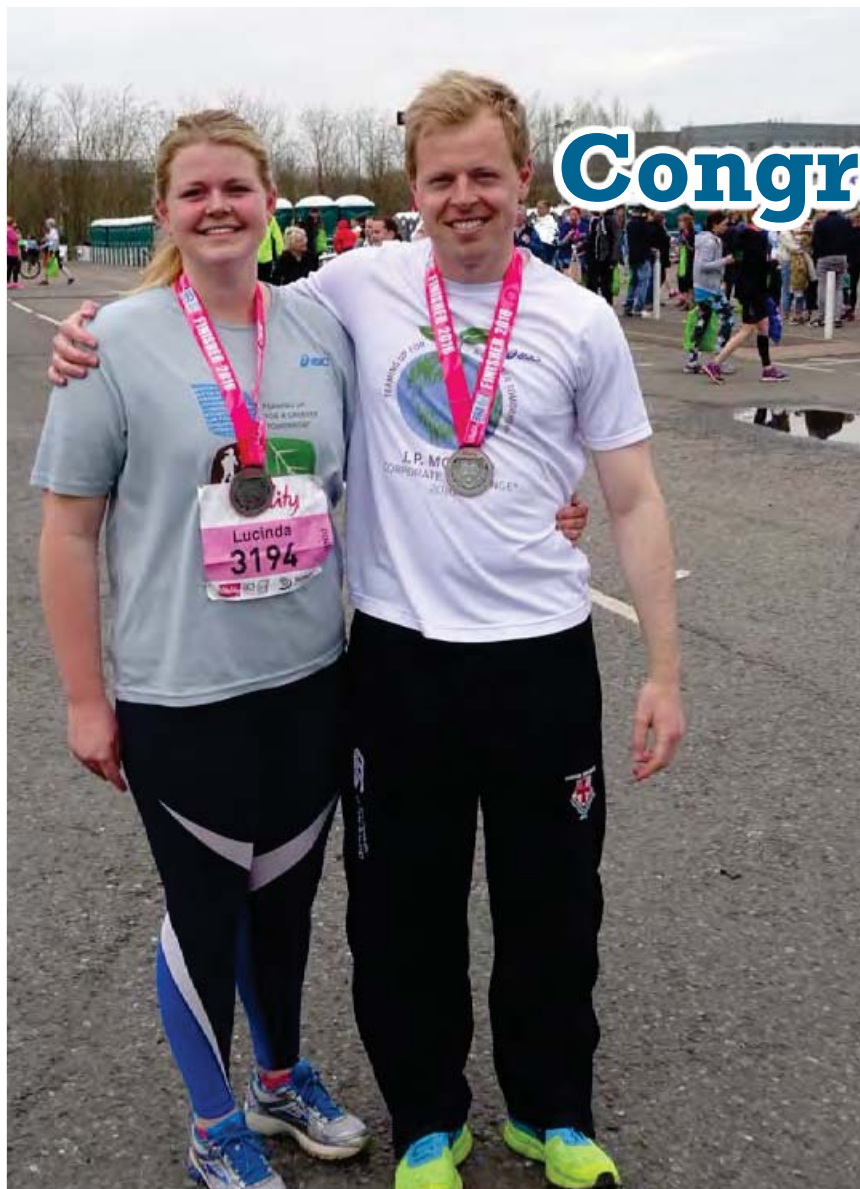
more Kidney Research to benefit the generations to come. That is what life is all about. Adding value.

Best wishes

**Michael Bending**  
**Chairman**  
**The Kidney Fund.**

*Contributions in memory of Carol and Alan:*

*South West Thames Kidney Fund c/o 42  
Woodcote Avenue, Wallington, SM6 0QY  
or c/o Mat Dibb, Renal Unit, St Helier H,  
SM5 1AA*



## Congratulations

To Tom and Lucy Atkinson who completed the Reading Half Marathon in 1hr 37 minutes, raising of an impressive £1,240 for The Kidney Fund.

Tom and Lucy are the grandchildren of Nick Lawson, who himself has helped raise several thousand pounds for The Kidney Fund over the past few years.

***Thank you from us all, to a very inspirational family.***



Sandra & Billy, presenting cheque to Dr Bending, Dr Phanish their Consultant and Dr Dockrell, Medical Director of the Institute

## You never know how strong you are, until being strong is the only choice you have.

A Mother's Tale... Sandra's son needed a transplant... Sandra was the donor. Together with help of their friends and family, they held an event and raised over £3,500.



# A message from your Chairman

Hopefully by the time you get to read this it will have warmed up and the sun will be shining.

This is a generally quiet time of year for the KPA but there is one important date for your diary

## Friday 17<sup>th</sup> June, Golf Day

Following the success of our previous golf days we are holding another event playing the superb Milford Golf Course in Surrey. The event will be held on Friday 17th June 2016. This is a lovely venue which will provide a great day of golf for players of all abilities. 2015's event was a great success and raised a significant amount for the KPA. It would be great to get 72 players for this year. If you're a golfer please book your place and bring a friend. A poster on the event is included within this edition.



## Purchase of Equipment

Since the last Renality we've purchased the following items

- Patient Exercise Equipment for St Helier
- Phlebotomy Chair for St Helier
- 2 Profiling beds for St Helier
- Patient Chairs & Lockers for St Helier
- 5 x Laptops for Pre-dialysis & Acute Nurses
- Patient Training Manuals/Information Booklets
- New Furniture, TVs & Blood Pressure machines for Beacon Ward.

This has only been possible due to the generous donations that we receive from patients, their families and friends, together with what we make on our Grand Draw at Christmas and our Golf Day so as always thanks to everybody who supports us and helps us to improve patients' lives.

## Other Matters

The KPA Committee still doesn't have patient representatives for Purley, Kingston and Crawley. Ideally we would love to have some younger Committee Members to enable us to represent the entire age range of St Helier's patients.

The position isn't onerous; we meet once a month in the Blue Room within the Renal Unit at St Helier at 7.30 on the first Tuesday of the month.

If you can help please contact me on 01483 426276 or email [daspensley@btinternet.com](mailto:daspensley@btinternet.com)

Best Wishes

**Dave Spensley**  
*Hon Chairman*

## KPA Donations...

St Helier and Surrey KPA would like to thank the following people for their much appreciated donations to either the KPA's general funds or the "No Place Like Home" appeal:

- Mr & Mrs P Steele
- Addiscombe Catholic Social Club
- The Worth Lodge
- Mrs Joy Hersey
- Mr & Mrs Smith
- Mr & Mrs Manfield
- Foresters Primary School
- Lisa Laing, friends and family
- British Legion, Worcester Park

# ***St Helier & Surrey KPA Golf Day***

In Aid of St Helier and Surrey Kidney Patients Association

Registered charity no 266391

***To be held on Friday 17th June at  
Milford Golf Course (Surrey)***

*The day will comprise of:*

*A Shotgun Start*

*A Singles Stableford Competition (full handicap)*

*Bacon Roll upon arrival*

*Three Course sit down (post golf) meal  
(advise any dietary needs)*

*Auction & Raffle*

***All for just £48 per person!***

For further details or to book a place  
please contact:

Paul Connolly

Hon. Vice Chairman

St Helier & Surrey KPA

5 Acorn Grove

Woking

Surrey

GU22 9PB

Phone: 07837 344 732

email: [connollypaul@hotmail.co.uk](mailto:connollypaul@hotmail.co.uk)



Cheques to be made payable to St. Helier & Surrey Kidney Patients Association

We have now been running the lottery for 301 weeks and with 50% being paid out in winnings we have paid out in excess of £32,800.00 in winnings with more than that being contributed to The Kidney Fund.

Thank you to all our members for their continued memberships without which we wouldn't have been able to make such a significant contribution.

Please encourage your friends, families and colleagues to join us as the more members we have then the more we can pay out in winnings which in turn increases the amount we can pass on to The Kidney Fund.

**The winning numbers and amounts over the last 6 months are:-**



Thank you very much.

Best wishes,

**Steven Clark**

*Administrator of The South West  
Thames Kidney Fund Lottery*

Home: 020 8404 8847

Office: 020 8835 9722

Mobile: 07800 607522

Skype: steveclark2605

16/10/2015	101035	Oxted	£162.50
23/10/2015	101062	Bletchingley	£163.50
30/10/2015	101148	Haslemere	£162.50
06/11/2015	101194	Bracknell	£162.50
13/11/2015	101158	Sandhurst	£163.00
20/11/2015	101004	Camberley	£164.00
27/11/2015	101154	Cheam	£164.50
04/12/2015	101008	Addlestone	£160.50
11/12/2015	101077	Farnham	£162.00
18/12/2015	101184	Morden	£163.50
25/12/2015	101193	Wallington	£163.50
01/01/2016	101241	Chipstead	£163.50
08/01/2016	101123	Guildford	£163.00
15/01/2016	101133	Sutton	£162.50
22/01/2016	101085	Ewell	£163.00
29/01/2016	101273	Cove, Farnborough	£162.50
05/02/2016	101276	Kenley	£163.00
12/02/2016	101308		£163.50
19/02/2016	101057	Kenley	£162.00
26/02/2016	101102	Frensham	£162.00
04/03/2016	101160	Belmont	£162.00
11/03/2016	101090	Staines	£162.50
18/03/2016	101287	Woking	£163.50
25/03/2016	101121	Addiscombe	£164.00
01/04/2016	101100	Croydon	£164.00

## KPA Memorial Donations...

St Helier and Surrey KPA would like to thank all of those individuals who have donated in memory of:

- Daniel O'Sullivan

# Lisa's Fabulous Fundraiser

**On** 17th January we held a fundraising event for St Helier and Surrey KPA. It was also my son Harry's 13th birthday and he wanted to mark the occasion by saying a huge thank you for the care I and our family have received over the last 27 years.

I was on dialysis at the unit in 1988, home dialysis in 1989 and received a transplant in 1990. That kidney lasted 24 years and I am now back on home dialysis. Harry has had one of his kidneys removed, and is seen at the children's unit for now but I'm sure will have his dealings with the adult services in the future.

Before the event we had such fantastic support from family, friends, neighbours and local businesses. Everyone joined in to collect and donate their time and money, raffle and tombola prizes, cakes, bottles etc.

My friend Linda and potential live donor had decided she was going to shave her hair off and dye it blond and then blue at the event and began raising sponsorship.

The 17th January arrived with a blanket of snow! Not to be defeated the BBQ and patio heater were fired up and the guests began to arrive, not put off by the cold weather. As our event got into full swing our VIP guests arrived, the Mayor of Sutton Mr Muhammad Sadiq and Mrs Mayor and Mr Tom Brake local MP.

They were shown my dialysis machine (Mr Leech) and were told about life on dialysis and the importance of organ donation. We had information boards on how are organs worked and how transplants save lives, organ donation cards and how to join the register, this information was kindly made and explained by our friend Molly.

The time arrived for Linda's head shave, the 150 people deep crowd cheered on as Mr Mayor made the first shave, followed closely by Mr Brake who held high a £10 note in one hand and his donor card in the other.

We continued the afternoon of fun with karaoke, BBQ, raffle, tombola, cake stall, nearly new stall, mini manicures and lots more.

On the day we raised £1,200.00 but once sponsorship and just giving totals were added we had a whopping grand total of £2,860.78! A huge thank you to all involved in making our day such a huge success.

**Lisa Laing**



From Left to Right: Linda, Mr and Mrs Mayor, Lisa and Harry



Tom Brake MP



Mrs Mayor, Lisa and Harry